Caregiver Impact of Autism Spectrum Disorder: Assessing Stress, Sense of Competence, and Relationship Satisfaction

by
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ABSTRACT

Title:
Caregiver Impact of Autism Spectrum Disorder: Assessing Stress, Sense of Competence, and Relationship Satisfaction

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While the impact of psycho-social variables has been evaluated for children with chronic illness and related disabilities, questions remain unanswered for families affected by ASD. Participants included 68 primary caregivers seeking services for a child aged fifteen months to 12 years suspected of or diagnosed with an ASD. Assessment tools included: 1. Parenting Stress Index-Fourth Edition-Short-Form (PSI-4-SF; Abidin, 2012), 2. Parenting Sense of Competence Scale (PSOC; Johnston and Mash, 1989), and 3. Relationship Assessment Scale (Hendrick, 1988). Independent samples t-tests were conducted to determine differences with a nonclinical control population (60 participants with a typically-developed child) regarding perceptions of stress, competence and relationship satisfaction. ASD caregivers reported experiencing significantly higher stress than Control caregivers (p=.000). A hierarchical multiple regression analysis was used to assess whether perceived competence and relationship satisfaction variables were predictors of overall stress in the clinical sample. Results indicate that these variables significantly impact parenting stress (p <.001). Implications for parent involvement in treatment and child outcomes are discussed.
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KEYWORDS

ASD
autism spectrum disorder
parenting stress
caregivers
relationship satisfaction
psychosocial variables
perceived competence
treatment impact
family centered approach
DEDICATION

This dissertation is dedicated to all those who have assisted and supported me on my academic journey and ultimate goal of becoming a clinical psychologist. To my parents, Robert and Kathleen Kline, who have always provided a constant reminder throughout the years that I can do anything. To my loving boyfriend and best friend, Neil Preston, as his love, comfort and positive attitude have made the stress of this journey bearable. To my sisters, Kaitlyn and Rosie Kline, as they have always and forever will be an incredible source of love and support. I also dedicate this project to a few of my fellow colleagues who have been an additional source of guidance. Your support and kind words have been greatly appreciated along my journey.
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CHAPTER ONE: INTRODUCTION

The Center for Disease Control (CDC) estimates that one in 88 children in the United States will eventually be diagnosed with an Autism Spectrum Disorder (ASD). ASD affects over 2 million individuals in the United States and tens of millions worldwide (Autism Speaks, 2013). This staggering statistic means that families, caregivers, teachers, medical professionals, and community members are all likely to be touched in one way or another by ASD. Understanding the characteristics of ASD and its impact on families and caregivers could substantially impact the manner in which therapeutic treatment and support is delivered to children experiencing difficulties.

According to the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5) (American Psychiatric Association, APA, 2013), ASD is a neurodevelopmental disorder that includes social and communication difficulties in addition to restricted or repetitive behavior, interests, or activities that lead to impairment across social, occupational, or other important areas of adaptive functioning. Social and communicative difficulties include problems with social-emotional reciprocity, nonverbal communicative behaviors, or developing, maintaining, and understanding relationships. Restricted or repetitive patterns of behavior or interests include: stereotyped or repetitive movements, insistence on sameness, highly restricted or fixated interests that are abnormal in intensity or
focus, and hyper or hypo-sensitivity to sensory input or unusual interest in sensory aspects of the environment.

Researchers (e.g., Charman, 2011; Fombonne, 2009; Klinger, Dawson, & Renner, 2003) have found ASD incidence and prevalence rates to be impacted by a number of variables, including variations in research methodology, heightened public awareness, decreasing age at diagnosis, broadened definitions, and the type of survey area. Regardless, there is a significant group of caregivers experiencing significant levels of parenting stress. The stress a caregiver experiences influences the family system, including social and adaptive functioning. More recently, research has indicated that parenting stress “has been identified as a risk factor for childhood maltreatment” (Abidin, 2012, p.52).

With ASD on the rise, there is an obvious need to examine medical causes, environmental influences, and treatment modalities for individuals with ASD. Until recently, research has focused heavily on the child, incorporating very little understanding or assessment of parental or familial difficulties. Karst and Vaughan Van Hecke (2012) proposed a model for intervention evaluation in their review of current interventions for ASD. The researchers urged professionals to consider parenting variables such as stress, perceived competence and relationship satisfaction in the evaluation and treatment of children. Karst & Van Hecke highlighted findings suggesting enhanced outcomes with increased parental involvement in intervention (e.g., generalization of skills acquired during
treatment). This notion is supported by researchers investigating parenting variables associated with the treatment of childhood disorders. Nock and Kazdin (2001) conducted a series of studies examining expectancies in parents of 405 children, ages 2-15, receiving treatment for oppositional, aggressive, and antisocial behavior. They found parental stress and depression were significant predictors of lower parent expectancies for child therapy. Furthermore, it was found parent expectancies predicted subsequent barriers such as decreased participation, attendance, and early termination in the treatment of their child.

**Parenting Stress**

In a recent report published by the American Psychological Association (APA; 2010), parental stress does not occur in only one type of household or with a specific type of child. Researchers surveyed 1,134 adults across the U.S, ages 18 and older. Of the sample, 1,037 were parents of children aged 8-17 years. The survey revealed that 73 percent of parents reported family responsibilities as significantly stressful. Parents also reported difficulties managing their stress. Interpersonal relationships are also impacted by caregiving. For example, Burr (1970) conducted a study with 147 middle-class intact couples and found abrupt overall changes in marital satisfaction in couples with younger children (i.e., preschool and school age). Couples raising a younger child reported a significant drop in marital satisfaction, with a slight gradual increase in satisfaction across areas
(e.g., finances, companionship, task performance) following school age and into the retirement stage for parents. Crnic and Greenberg (1990) conducted a longitudinal study with 74 mother-child dyads in which the age of the child ranged from one month to five years old. The authors found minor parenting hassles (e.g., daily events involving challenging behavior) to be a source of stress for mothers and hassles were associated with lower ratings of parenting satisfaction and family functioning.

Taking these findings into consideration, it is suspected that a caregiver who invests significant resources, such as time, energy, care, and money to a child with chronic illness or disability experiences higher levels of stress in comparison to those caregivers who do not. Additionally, research has shown that caregivers experiencing stress are at risk of utilizing maladaptive methods to handle their child’s difficulties. Raphael, Zhang, Liu, and Giardino (2009) examined the prevalence of parenting stress in U.S. families and associated socio-demographic variables thought to be associated with parenting stress. Results indicated that 12.6 percent of American children lived in a household in which at least one parent was experiencing high parent stress. A positive correlation was identified for households with high parenting stress and increased pediatric emergency care visits and a higher number of outpatient child sick visits to primary care than those families coping well with parenting. Taking these findings into consideration, it is suspected that a caregiver who invests more resources (e.g., time, energy, care, money) for a
child with a chronic disability will experience higher levels of stress in comparison to those caregivers who may not have to provide more of such resources.

In fact, recent research indicates that caregivers raising a child with chronic illness, developmental disability, or behavioral problems do experience higher stress levels with regard to their child than parents with a child who is neurotypically developed (Delambo, Chung, & Huang, 2011; Gupta, 2007; Feldman et al., 2007). Bebko, Konstantareas, and Springer (1987) examined perceived stressors for parents of children with ASD enrolled in a summer care program. Results showed that parental perception of severity of ASD characteristics correlated with the degree of parental stress. Specifically, language deficits, cognitive impairment, and performance related to cognitive abilities were judged to be by parents as the most severe of the child’s difficulties. Additionally, lower symptom severity level for older children (>8.5 years) was accompanied by lower stress levels for mothers, but not for fathers. Finally, professionals judged parents as more stressed by their child’s symptoms than did the parents themselves. Additional characteristics, such as the gender of the child, number of children in the family, birth order, SES, and employment status of the mother were not related to the degree of parent stress.

Researchers have also found that parenting stress may present as specific profiles in caregivers who have a child with ASD. Koegel et al. (1992) examined perceptions of stress for 50 mothers of children with ASD across a number of
cultural and geographic environments (California, West Virginia, and Germany). The children ranged in age from 3.1 years to 23.1 years and functioning levels ranged from severely impaired and untestable to near normal on standardized tests. Results identified a characteristic profile that was highly consistent across the factors on scales measuring stress associated with dependency and management, cognitive impairment of the child, limits on family opportunity, and life-span care. Correlation coefficients between all subgroups were high for the geographic locations, age of the child (younger: <7 years versus older: 7 years or older), and the intellectual functioning levels (IQ of <50 versus >50). Koegel et al. also identified differences between the normative group and ASD groups regarding the level of concern associated with the continued dependence of a child into adulthood (i.e., parents of children with ASD indicated a higher level of concern).

Stress levels in caregivers impact a child’s progress in treatment. For example, Baker-Ericzen, Brookman-Frazee and Stahmer (2005) measured stress levels before and after involvement in an inclusive toddler program for 37 children with ASD and a normative group of 23 children. Overall, a significant effect was found between parent stress and participation in the toddler school inclusion program. Significant changes in stress level of the mother related to improvements in child characteristics such as cognitive functioning, social interaction, and ASD symptoms. Child characteristics were identified to be predictive of stress levels in both parents for children with ASD. Kundert and Trimarchi (2006) also found that
parental involvement impacts the effectiveness of intervention for children with ASD.

**Parenting Stress and ASD**

As discussed, caregivers of children with ASD are at a higher risk for increased levels of distress (e.g., Estes et al., 2009). Mancil, Bedesem, and Boyd (2009) conducted a meta-analysis of 19 studies and found that parents consistently reported stress associated with raising a child with ASD. Over the past two decades, researchers have identified different characteristics of both caregiver and child that contribute to stress in the role of parenting a child with a disability. Estes et al. (2009) noted factors that influence stress in caregivers, including impaired adaptive functioning and added caregiving responsibilities.

Konstantareas and Homatidis (1989) investigated child and family characteristics associated with raising a child with ASD. The characteristics included: symptom perception, sex, age, cognitive level, verbal ability, hyperirritability, facial oddity, birth order, self-abusive behaviors, seizures, and sleep disturbance. The most severe-rated symptoms by parents included deficits in verbal communication, cognitive ability discrepancy, and impairment in social interaction. Children with low intellectual functioning, and those who were nonverbal were rated as more severely autistic. For mothers, hyperirritability and older age were associated with elevated stress scores. For both mothers and fathers, the best predictor of stress was a child’s self-abuse, which was correlated with
feelings of fear and helplessness in parents. Parents were also found to attribute their child’s behavior to their own inability to parent and feelings that their child could not relate appropriately to them (p. 467-8).

More recently, Duarte, Bordin, Yazigi, and Mooney (2005) examined determinants of maternal stress for 31 mothers of children with ASD and 31 mothers of children without mental health difficulties. Poor expression of affect, little interest in people, being an older mother, and having a younger child contributed to increased stress levels. The authors concluded that mothers of children with ASD are more prone to experiencing stress.

Cultural aspects have also been examined with parenting variables. Delambo, Chung, and Huang (2011) examined parental stress across Asian American and non-Asian American parents of children with developmental disabilities. Delambo et al. examined correlations with the age of a child, the child’s developmental disabilities, and the age of the caregiver in relation to parent stress level. While both cultural groups reported high stress levels, researchers found Asian American parents experienced a significantly higher level of stress related to children’s characteristics than the non-Asian American parents. Child’s age was the best correlate of parental stress for non-Asian American parents and age of parents was the best correlate of parental stress for Asian American parents. Older Asian American parents tended to report a lower level of parent functioning stress than did younger Asian American parents. The authors interpret this finding
to be reflective of an Asian culture in that older parents may use more resources such as social support and community connections. Research has also indicated (e.g., Konstantareas & Homatidis, 1989) caregiver age to be related to stress levels. Konstantareas and Homatidis (1989) examined parents of a child with a learning disability and found that parents under the age of 40 experienced greater child adjustment problems and concomitant parental stress.

Gupta (2007) explored the relation between the type of disability and demographic variables in families impacted by a child with ADHD, developmental disability (i.e., cerebral palsy, mental retardation, and ASD), HIV infection, or asthma, and families of a child who was typically developed. Parents of a child with ADHD and those of a child with a developmental disability reported higher total stress than parents of a chronically ill (HIV, asthma) child and those who had a typically developing child. Parents with a child with ASD had highest scores of stress in all parent-domains of assessment, except attachment. Gupta reported factors such as role restriction, poor health, and isolation as influential in perceived parental stress in parents with developmentally delayed and behaviorally disruptive children.

In addition to heightened stress, raising a child with an ASD may lead to dysphoria and low self-concept. For example, Dumas, Wolf, Fisman, and Culligan (1991) examined differences in parental reports of stress, child behavior problems, and dysphoria in 150 families with a child with ASD, Down syndrome, or a
typically developed child. Parents of children with ASD and behavior disorders experienced higher levels of stress and dysphoria related to parenting exceptional children than parents in the other two groups. Furthermore, parents of children with behavior disorders reported their children presented significantly more difficulties that were more intense than other children’s behaviors.

Mothers of children less than 7 years old with ASD reported greater dysphoria than mothers in the other groups. Furthermore, mothers of younger autistic children reported greater dysphoria than mothers in the other three groups. The authors suggested higher feelings of dysphoria to be reflective of behavioral characteristics rather than depressive symptoms experienced by the parents, in that a connection was found between dysphoria and stress associated with parenting a difficult child.

Research has also indicated that depression and parental self-efficacy to be related to caregiving for a child with a chronic illness. In addition, social support influences the caregiver’s psychological well-being. Feldman et al. (2007) examined depressive symptoms and other psychological variables in 178 parents with children who had developmental delay (DD) such as cerebral palsy, developmental epilepsy, spina bifida, fetal alcohol syndrome, pervasive developmental disorders (including ASD), Down syndrome, and brain damage. In this study, 20%, or 35 of the caregivers (22% of biological mothers), exhibited elevated scores, suggestive of clinical levels of depression. Participants with higher
levels of depression also indicated higher child behavior problems, escape-
avoidance coping scores, lower social support, and lower parental self-efficacy.
However, social support was found to mediate and marginally moderate the
relationship between parental stress and child adaptation. The researchers
postulated negative ratings by depressed mothers or higher sensitivity in depressed
mothers in detecting child problems may have increased ratings of depressive
symptoms in mothers with children with behavioral difficulties.

Dunn, Burbine, Bowers, and Tantleff-Dunn (2001), examined the
relationship between stressors, social support, locus of control, coping styles and
negative outcomes, namely, depression, social isolation, and spousal relationship
problems among parents of children with ASD. They surveyed 58 parents who had
a child with ASD between the ages of 3 and 15 years and found social support and
coping style moderated stressors and negative outcomes of the caregiver. Higher
levels of social support corresponded to fewer spousal problems. Coping styles
were also found to be more predictive of spousal problems. Taken together, studies
investigating parenting variables associated with children with ASD have
demonstrated caregivers encounter heightened stress and other inter and intra
personal difficulties when raising a child with a disability, than those raising neuro-
typically developed children.
**Perceived Parental Competence**

The literature indicates that a caregivers’ perception of their competence may influence stress and relationship satisfaction (Hastings & Brown, 2002; Johnston & Mash, 1989; Kazak & Marvin, 1984). According to Pisterman et al. (1992), perception of parental competence impacts child care.

Parental competence has been defined and described in a number of ways. Researchers have regarded the terms “self-efficacy” and “competence” similarly when investigating the level of perceived knowledge a caregiver has in the parenting role. Hastings and Brown (2002) defined self-efficacy or a caregiver’s competence via Bandura’s theory of self-efficacy; “perceptions of one’s skills in a given domain…[which]…is likely to vary for different behaviors in different contexts” (p. 222). Further, they noted self-efficacy is often viewed as “feelings of parental competence” when investigating self-efficacy as an outcome variable and not as a predictor variable (p. 223). Another way to understand the term competency would be to view it as one component of “parent self-esteem” (Johnston & Mash, 1989) in which self-efficacy is “the degree to which a parent feels competent and confident in handling child problems” (p. 167). Johnston and Mash also stated parenting self-esteem as comprised of the “…quality of affect associated with parenting or the degree of satisfaction derived from the role” (p. 167). This study will use the term parental competence as defined by Johnston and
Mash (1989) to describe caregivers’ perceptions of how they view themselves as having the ability to complete tasks associated with parenting.

Parental competence appears to be an important factor to when researching the domain of caregiver stress and perhaps with relationship satisfaction. Research has already demonstrated a correlation between parental self-efficacy and a caregiver’s anxiety and depression. Hastings and Brown (2002) investigated self-efficacy, anxiety, and depression for 46 parents (26 mothers and 20 fathers) of children with ASD. Regression analyses showed self-efficacy mediated the effect of child behavior problems on mothers’ anxiety and depression and moderated the effect of child behavior problems on father’s anxiety.

The researchers determined high levels of potential mental health difficulties in parents of children with ASD and that parents may be affected differently by their child. Furthermore, they identified self-efficacy as a protective factor against the risk for anxiety for fathers with children with problematic behaviors in which fathers who had high self-efficacy were less anxious than those with low self-efficacy when their child had a high level of behavior problems. However, the researchers noted when the child exhibited low levels of problem behavior; father’s self-efficacy had no effect on their anxiety. These findings contribute to the understanding that perceptions of self-efficacy or parental competence can influence stress levels in caregivers in a positive way. This notion that perception of competence has been shown to have positive effects in the care of
a child has also been demonstrated in another study focusing on parents of a child with ASD (e.g., Pisterman et al., 1992).

Parenting competence has been investigated in relation to additional aspects of the caregiver’s life, including stress and marital satisfaction. For instance, Kazak and Marvin (1984) investigated individual, marital, parenting stress, and social support in 109 families with and without a child with a disability. Fifty-six families with a child with spina bifida were compared to a group of 53 families without a child with a disability.

Kazak and Marvin found higher levels of stress for families with a child with a disability. Further, they found stress was related to the parenting relationship as mothers with a child with a disability viewed their child as less physically and socially adaptive, more demanding, less attractive, less intelligent, or less pleasant than what the mothers had expected in their child. Stress, frustration and depression in mothers did not differ from the comparison group in terms of viewing their children as problematic in activity level or at risk for more mood disorders. Mothers of a child with a disability reported lower maternal competence as the comparison group and marital satisfaction presented no group differences. Interestingly, higher perceived levels of affection were found in families who had a child with spina bifida. Despite high levels of stress in the groups, successful coping strategies by parents were found.
Relationship Satisfaction

Research indicates that caring for a child with an ASD impacts the caregiver’s satisfaction with family relationships, such as partnerships or marriages. Satisfaction with the relationship, just as satisfaction of the individual in the parenting role, is also assumed to be impacted by stressors.

It is plausible to suggest couples with limited perception of competence and increased stress experience less satisfaction in their relationship when raising a child with a chronic disability than a couple whose child may not require additional time or resources. Research has indicated parents of children with an ASD present more expressions of marital or relational dissatisfaction than those whose children have other disabilities (for review, see Mancil, Bedesem, & Boyd, 2009).

Brobst, Clopton, and Hendrick (2009) examined relationship quality and parental stress for 45 caregivers (25 couples whose child had ASD and 20 couples without a developmental disorder). The level of the child’s needs was assessed by the intensity level and number of behavior problems the couple experienced. The age range of the parents was from 23 to 55 years, with a child ranging in age from 2 to 12 years. They compared the two groups of couples on stress variables and relational variables, correlations among these variables, and the prediction of relationship satisfaction.

Parents of children with ASD reported more parental stress and greater trouble with child behavior problems and lower total social support and relationship
satisfaction than did parents in the comparison group. Higher stress levels were associated with the child’s disability and intensity level parents perceived to be more severe. It is important to note couples did not differ on perceived spousal support, respect for their partners, or commitment to their relationships.

Additionally, Bristol, Schopler, and Gallagher (1988) assessed whether having a young developmentally disabled or nondisabled male child affected adaptation and family roles for mothers and fathers in 56 two-parent families with 31 developmentally disabled boys and 25 nondisabled boys. Marital adjustment, family life disruptions, and observed parenting of the child, but not depression, were found to vary with disability status of the child. Mothers with a child with and without a disability reported more depressive symptoms and family disruption than fathers of disabled children. Disagreement in spousal support was a significant negative predictor of perceived and observed parental adaptation; parents, especially fathers of disabled children, reported significantly more marital difficulties than their peers with non-disabled children.

Consistent with the aforementioned studies, Rodrigue, Morgan, and Geffken (1990) examined parenting competence, marital satisfaction, family cohesion, and family adaptability in mothers of 20 autistic, 20 Down syndrome, and 20 developmentally normal children. Rodrigue et al. used the Parenting Sense of Competence Scale (Gibaud-Wallston & Wandersman, 1978) and other measures to assess perceived parenting competence, marital satisfaction, and family cohesion.
and adaptability. They found mothers of a child with an ASD reported less parenting competence, less marital satisfaction, more family cohesion, and less family adaptability than mothers in the other two groups. Marriages were reportedly less satisfying for mothers of girls with ASD than for mothers of boys with ASD, whereas the reverse was true for mothers of developmentally normal girls and boys. Mothers of a child with ASD or Down syndrome reported more disrupted planning, caretaker burden, family burden, and frequent use of self-blame as a way to cope than those mothers who had developmentally normal children.

These findings regarding stress, perceived competence, and relationship satisfaction also leads one to question the divorce rate among couples who have a child with ASD. Some research has shown that child developmental disorders, including ASD, may correlate with higher rates in divorce. Hartley et al. (2010) investigated divorce in parents of children age 10 or older with an ASD and a matched representative sample of parents of children without disabilities by use of in-home interviews, telephone calls, and self-administered measures. They compared the occurrence and time of divorce in 391 parents who had a child with an ASD.

Parents of children with an ASD had a higher rate of divorce than the comparison group and divorce remained high throughout the course of the child’s development for a family with a child with ASD. A decreased rate was found following the son or daughter’s childhood in the comparison group. Furthermore,
younger maternal age at the time of the birth of the child with ASD and birth order (child with ASD born later rather than earlier) positively predicted divorce in parents with a child with ASD. Additionally, the risk of divorce for parents of a child with ASD remained higher throughout the child’s adolescence and early adulthood and did not decrease until the child reached age 30.
CHAPTER 2: STUDY PURPOSE

Ample research examines ASD within the child domain, less emphasis has been placed on the parental and relationship variables associated with raising a child with an ASD. More research is needed to understand competence, stress, and relationship satisfaction in parents or caregivers and how these variables impact and functioning.

Research has shown parents experiencing distress, decreased sense of competence, and satisfaction can negatively impact the lives of family members and the intervention of ASD and other disorders. In addition to determining the cause and most efficacious treatments for ASD, psychosocial factors that caregivers encounter must also be incorporated as these factors are likely to impact a child’s treatment outcomes (Baker-Ericzen, Brookman-Frazee & Stahmer, 2005; Kundert & Trimarchi, 2006). The current study utilized three standardized questionnaires to examine caregiver’s perceptions of stress, relationship satisfaction, and sense of competence.

This study extends the existing literature by incorporating two additional variables, the perception of parental competency and relationship satisfaction in relation to stress. These additional variables may be predictors of the overall degree of stress a caregiver is likely to experience. The aim of this study was to gain insight into the relationship between competence and relationship satisfaction (i.e.,
level of relationship support) as predictors to level of stress. Measures included the PSI-4-SF, PSOC, and the RAS in which scores from the clinical group were compared with a control group (parents with a typically developed child). The following hypotheses have been devised:

**HYPOTHESIS I.** Caregivers with a child with ASD will demonstrate lower levels of perceived parental competence when compared to parents of a non-clinical sample (Kazak & Marvin, 1984; Rodrigue, Morgan, & Geffken, 1990; Pisterman et al., 1992; Hastings & Brown, 2002).

**HYPOTHESIS II.** Caregivers with a child with ASD will demonstrate lower levels of relationship satisfaction when compared to parents of a non-clinical sample of children (Bristol, Gallagher, & Schopler, 1988; Rodrigue, Morgan, & Geffken, 1990; Brobst, Clopton, & Hendrick, 2009; Hartley et al., 2010).

**HYPOTHESIS III.** Caregivers with a child with ASD will have a higher stress level than caregivers without a child with ASD. (Dumas, Wolf, Fisman, & Culligan 1991; Dunn, Burbine, Bowers, & Tantleff- Dunn, 2001; Gupta, 2007).

**HYPOTHESIS IV:** Perceived parental competence and relationship satisfaction will predict variance in parental stress, such that increased levels of parental competence and increased levels of relationship satisfaction will lead to
lower levels of parental stress (Hastings & Brown, 2002; Johnston & Mash, 1989; Kazak & Marvin, 1984; Brobst, Clopton, & Hendrick, 2009).

**HYPOTHESIS V-VII:** Differences will exist between parenting stress, perceived competence, and relationship satisfaction in relation to age of the child (Konstantareas & Homatidis, 1989; Duarte, Bordin, Yazigi, & Mooney, 2005) among caregivers in the ASD group. Three hypotheses are proposed with regard to the target child age:

**Hypothesis V:** Caregivers with an older child will demonstrate lower parenting stress level (based on the total PSI-4-SF score) when compared to caregivers with a younger child.

**Hypothesis VI:** Caregivers with an older child will demonstrate a higher sense of parental competence (based on the total PSOC score) when compared to caregivers with a younger child.

**Hypothesis VII:** Caregivers with an older child will demonstrate a higher level of relationship satisfaction (based on the RAS average score) when compared to caregivers with a younger child.

**HYPOTHESES VIII-X:** The age of the caregivers of a child with ASD will also be taken into account. Research has shown mixed findings regarding the age of the caregiver and perceptions of overall stress in caregivers who have a child with a developmental disability (Delambo, Chung, & Huang, 2011; Konstantareas &
Homatidis, 1989). Three hypotheses have been developed with regard to caregiver age:

Hypothesis VIII: Older caregivers will demonstrate lower level of parenting stress when compared to younger caregivers.

Hypothesis IX: Older caregivers are likely to have higher levels of perceived parental competence when compared to younger caregivers.

Hypothesis X: Older caregivers will demonstrate a higher level of relationship satisfaction when compared to younger caregivers.

HYPOTHESIS XI: The gender of the target child will also be taken into account for caregivers with a child with ASD as some research has found that the gender of the child did not influence caregiver stress (Bebko, Konstantareas, & Springer, 1987). Consistent with this finding, it is hypothesized that no significant differences will be found between levels of parental stress for caregivers of male children and caregivers of female children. This relationship will be examined via an independent t-test.
CHAPTER THREE: METHOD

Participant Recruitment

Caregivers were recruited from mental health organizations in the state of Florida, including the Scott Center for Autism Treatment at the Florida Institute of Technology, health fairs, outreach events, and through the use of the internet by conducting a website survey. The age of the caregiver and the age of the child were categorized as older or younger. Younger caregivers were categorized as 18 to 39 years old and older caregivers were categorized as 40 years old or older as inferred by Collis-Moore (1984). A younger child was categorized as seven years or younger and an older child as eight to eighteen years old as used by Koegel et al. (1992). The clinical population (68 participants) involved caregivers seeking services with outpatient autism clinics. The special inclusion criteria for participants of either the ASD Caregivers or Control Caregivers required that the caregiver have a target child ranging in age from zero months to 12 years. The nonclinical sample (60 participants) required parents over the age of 18 years with at least one neurotypically developed child, ranging in age from zero months to 12 years. For the clinical sample, the target child required a diagnosis of ASD or that there was a suspicion of ASD on behalf of a mental health professional. Participants of all races and both genders were included in the study.

Participants

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The educational level of participants ranged from less than the ninth grade education level to the graduate or professional degree level. Estimated household income ranged from less than $25,000 to $75,000 and above. For the ASD caregivers, ASD severity was ranked by the caregiver as: very mild, mild, moderate, severe, or very severe. The age of the child when the child received a formal diagnosis of ASD was also assessed. Caregivers were asked about services they had used for their child or if they had participated in parent training, support groups, marital strengthening groups, self or community programs, respite or crisis intervention programs, transitional housing, family services, academic tutoring, early intervention services, or employment services.

The caregiver surveys were administered via internet or in-person. For those requesting services with the Scott Center for Autism Treatment as part of the Learning to Live with Autism parent training program (funded in part by the Harper Family Foundation and Agency for Persons with Disabilities; grant #: 201620), the researcher and clinic staff distributed packets to those parents requesting evaluations or behavioral intervention services. Participants were informed that their participation in the study was voluntary and those who chose to participate were not given any compensation. Participants’ names and other identifying information were not included on the demographics questionnaire or for any of the assessment measures. For those surveys completed in-person, informed consent forms were
kept separate from their corresponding research packets in order to maintain the anonymity of the participants. Online informed consents contained a box indicating whether the participant understood the study and wished to participate.

**Assessment Measures**

A demographic survey was used to gather information to test variables including caregiver age, target child age, and gender of the target child. The study employed measures that capture perceptions of parental competence, stress, and relationship satisfaction. The study used the Parenting Sense of Competence Scale (PSOC) developed by Johnston and Mash (1989), the Parenting Stress Index-Fourth Edition-Short-Form (PSI-4-SF; Abidin, 2012), and the Relationship Assessment Scale (RAS; Hendrick, 1988).

**Demographics**

A brief demographic survey was included with the PSOC, PSI, and RAS assessments for caregivers. The demographic survey was used to gain additional information concerning age and gender of the parent and target child, total number of children living in the home, total home income, caregiver ethnicity, and formal sources of support for the participant or the participant’s child. Participants in the ASD group were also asked to provide information concerning their child’s
diagnosis, age at diagnosis, and their perceptions of ASD symptom severity. The following sections are descriptions of the three scales used in the current study.

**Parenting Sense of Competence Scale (PSOC)**

The Parenting Sense of Competence Scale (PSOC; Johnston & Mash, 1989) assesses the degree to which parents feel they possess the skills and understanding to be an adequate parent and also their level of satisfaction with the parenting role. As discussed previously, Johnston and Mash defined parenting self-esteem as having both components of Efficacy (the degree of capability and competence the parent feels he or she has in the parent role) and Satisfaction (level of overall contentment within the parent role). The scale consists of 16 statements rated on a six-point scale ranging from strongly agrees to strongly disagree. Efficacy (scores ranging from 7 to 42) and Satisfaction (scores ranging from 9 to 54) scales are added together to yield a total score and reverse scoring is used for some items in which higher scores indicate greater parenting self-esteem (Ohan, Leung, & Johnston, 2000). As discussed previously, the measure appears to be largely psychometrically sound. The current study included both the Efficacy and Satisfaction scales in the interpretation and scoring of the PSOC score.

**Parental Stress Index/Short-Form/Fourth Edition (PSI-4-SF)**

The measure consists of 36 items assessing the degree and cause of stress in the parent-child relationship. There are three subscales: Parental Distress (PD), Parent-Child Dysfunctional Interaction (P-CDI), and Difficult Child (DC). Abidin
(1995) originally developed the PSI-SF through conducting a factor analyses of data originally collected from mothers who completed the full-length PSI. All items are presented and scored as one would for the PSI-4. PD items from the PSI-4 pertain to subscales capturing depression, role restriction, isolation, and partner relationship. P-CDI items are derived from both the Parent and Child Domain scales and represent items pertaining to parenting style and attachment in addition to the parent’s level of satisfaction with the child-interaction. DC items are taken from PSI-4 items that are comprised of child characteristics such as temperament, adaptability, mood, attention and impulsivity. This subscale provides information regarding how the parent perceives the child’s behaviors.

The PSI-4-SF also detects defensive responding, positive impression, or problem minimization of negativity in the caregiver’s relationship with the child. Scoring involves adding the numbers in each category together to equal the total score. The total score measures the overall stress the parent is experiencing in his or her parental role. Raw scores are converted to percentile scores. A score falling between the 16th and 84th percentile is considered typical. High scores are at or above the 85th percentile and scores falling in the 90th percentile or higher are considered clinically significant (Abidin, 2012). The measure appears to be largely psychometrically sound. Therefore, this study incorporated the total stress raw score in the analysis of parenting stress.
**The Relationship Assessment Scale (RAS)**

The Relationship Assessment Scale (Hendrick, 1988) assesses for relationship satisfaction in marital or romantic relationships. Vaughn and Baier-Matyastik (1999) explained the RAS as a measure of global relationship satisfaction. The scoring system is a 5-point Likert scale and either the total or average score can be used for interpretation. Relationship satisfaction scores are obtained by adding responses together and dividing by 7 and items 4 and 7 have recersed scoring. Sample items include “How good is your relationship compared to most?” or “How much do you love your partner?” and ratings range from A (Poorly) to C (Average) and E (Extremely Well). Average scores range from 1 to 5. Scores over 4.0 would likely indicate non-distressed partners. Scores of 3.5 for men and between 3.5 and 3.0 for women would indicate greater relationship distress and dissatisfaction (Hendrick, Dicke, & Hendrick, 1998). As discussed previously, the measure appears to be largely psychometrically sound. This study employed the average of the item responses in the analysis of relationship satisfaction in both the clinical and non-clinical samples.

**Procedure**

An introductory letter, informed consent form, and caregiver survey were provided to parents who expressed interest in participating in the study. Participants were informed that there was no obligation to complete the questionnaire and those responses would be kept confidential. Caregivers in the
clinical population completed the packet as part of procedural assessments administered at initial clinical interviews or they participated in the study via an online survey. Participation from caregivers of the control sample was obtained via in-person, on the researcher’s university campus, or by the internet via survey website.

For both the clinical and control group, caregivers were given the opportunity to contact the researcher to set an appointment time or they chose to complete the survey online. When completing the measures on-line, the participant was given contact information of the researcher and a link to take the survey. The survey also included the demographic questions. The entire survey (demographic questions, PSI-4-SF, PSOC, and RAS) was completed in 30 to 45 minutes by most participants.

**Design**

The current study examined parenting stress, perceived parental competence, and relationship satisfaction across two groups: a clinical sample of parents with a child with ASD and a nonclinical or control sample of parents who have a neuro-typically developed child. Total scores obtained from all three measures (PSI, PSOC, and RAS) were obtained by both groups. To obtain power for the statistical analyses of data, each variable (i.e., parenting stress, perceived parental competence, relationship satisfaction, caregiver age, child age, and child gender) required approximately 10 participants each, yielding 60 participants for
each group and a total of 120 participants combined. The current study was reviewed and approved by the Institutional Review Board at Florida Institute of Technology.
CHAPTER FOUR: DATA ANALYSES

Descriptive statistics were performed to assess demographic variables of the clinical and non-clinical groups. The specific variables included: mean age of the caregiver and child, percentage of female and male caregivers and children, and the average number of children living in the household. Additional characteristics such as caregiver ethnicity, educational level, income status, and marital or relationship status were compared. For both groups, types of services the individual, child, or family are using and the length of such services were also compared. Pertaining to the clinical group, average age of the diagnosis of the target child and severity ranking were included in the descriptive statistics. Differences between groups on the main demographic variables were examined using a nonparametric technique.

Main Analysis

To analyze hypotheses I through III, independent samples t-tests were performed to determine whether there were significant differences between the mean scores obtained from both populations for perceived stress (PSI Total Raw Score), competence (PSOC Total Score), and relationship satisfaction (RAS Average Score). Effect sizes were obtained with the use of eta squared or Cohen’s D statistics. To analyze hypothesis IV, a hierarchical multiple regression analysis was used in that levels of parental stress were predicted using perceived competence and relationship satisfaction in the clinical sample. To address
hypotheses V through VII, independent samples t-tests were applied to determine if significant differences existed between the older versus younger caregivers, older versus younger children, and male versus female children. Effect sizes of these tests were also be obtained with the use of eta squared statistics.
CHAPTER 5: RESULTS

Clinical Group Characteristics

Information for demographic variables was obtained from the ASD and Control caregivers. Group 1, or the ASD Caregivers, was composed of 68 participants; 49 (73.1%) females and 18 (26.9%) male caregivers. The majority of the surveys were completed by caregivers who sought treatment for their child’s ASD symptoms at a autism treatment facility. Three participants in this group were recruited from two outreach community events and six participants completed the research project through an online survey tool.

The average age of the participants in the ASD Caregiver sample was 39.08 years ($SD= 8.702$) and participants ranged in age from 23 to 66 years. With regard to ethnicity, 53 (80.3%) participants identified as White, one (1.5%) identified as Black or African-American, five (7.6%) caregivers identified as Hispanic, one (1.5%) identified as Native Hawaiian, and six (9.1%) identified as of Asian ethnicity. With regard to relationship status, 48 (70.6%) participants reported being married, 14 (20.6%) reported being separated/divorced, five (7.4%) reported being single/never married, and one (1.5%) identified as partnered. The education level of the group included 21 (32.3%) caregivers with some college completion, 17 (26.2%) with a bachelor’s degree, 10 (15.4%) with an associate’s degree, 10 (15.4%) with a graduate or professional degree, three (4.6%) with completion of
high school, three (4.6%) with some high school, and one (1.5%) with less than
ninth grade completion. Three (4.4%) of the participants did not indicate their
educational status.

Results regarding family and child demographic variables were also
obtained. The average number of children in the home was 2.03 ($SD= .930$),
ranging from one to five children. 60 (89.6%) caregivers endorsed themselves as
birth parents, three (4.5%) caregivers indicated they were grandparents, two (3.0%)
as adoptive parents, and two (3.0%) caregivers as siblings. Results further show, 16
(24.6%) participants endorsed an annual income of less than $25,000, 16 (24.6%)
participants reported an income between $25,000 and $49,999, 13 (20%) indicated
an income between $50,000 and $74,999, 12 (18.5%) participants reported a
household income of $75,000-99,999, and eight (12.3%) reported a household
income of $100,000 or more. Three participants (4.4%) did not indicate their
estimated household income.

The target child (or a child with ASD) consisted of 18 (26.5%) females and
50 (73.5%) males. The average age of the target child was $5.7822$ ($SD= 3.11$), with
an age range of 19 months to age 12. Fifty three (81.5%) caregivers rated their
child as having been diagnosed with ASD, eight (12.3%) caregivers indicated
seeking a formal evaluation of suspected ASD, three (4.6%) indicated a secondary
or co-morbid diagnosis of ADHD, and one (1.5%) selected “Other” diagnosis in
addition to ASD. Three (4.4%) participants did not endorse a formal diagnosis. Severity of ASD symptoms were also obtained by caregivers. 19 (41.3%) participants indicated Mild symptoms, 18 (39.1%) indicated Moderate symptoms, five (10.9%) indicated Very Mild symptoms, two (4.3%) indicated Very Severe symptoms, one (2.2%) indicated Severe symptoms, and one (2.2%) did not endorse a severity level. It should be noted there were a total of 22 missing responses of this item as some participants did not indicate a response. Also, symptom severity was subjectively based on the caregiver perceptions of their child’s display of ASD symptoms and many caregivers expressed to the caregiver uncertainty and therefore, chose not to answer the question. Data pertaining to the types of individual or family healthcare programs or services utilized by caregivers at the time of their participation were also ascertained. 36 (63.2%) caregivers reported receiving multiple sources of formal support, nine (15.8%) reported receiving no sources of formal support, five (8.8%) reported receiving early intervention services, two (3.5%) reported receiving family and child counseling, two (3.5%) reported “Other” sources of support, and one (1.8%) participant indicated self or community support, parent-child therapy, or parent education services, see Appendix A, Table 1.
Non-Clinical (Control) Group Characteristics

The Control group included 60 caregivers who were recruited through the use of community internet forums and social media sites. Fifty-four of the participants completed the research project through an online survey tool. Additionally, six participants were recruited from the researcher’s school campus. The mean age of the caregiver was 33.34 (SD=5.599) and participants ranged in age from 22 to 44 years. Due to an error in the online survey administration, 25 of the 60 caregivers did not have the opportunity to indicate their age. Therefore, results regarding the mean age of the Control group are based on 35 participants and were not analyzed further than descriptive analyses.

Of 39 caregivers who indicated their gender, 36 (92.3%) were females and 3 (7.7%) were males. With regard to ethnicity, 54 (93.1%) participants identified as White, two (3.4%) identified as Hispanic, one (1.7%) identified as Asian, and one (1.7%) identified as two or more ethnicities. Two (3.3%) did not endorse an ethnicity. For relationship status, 50 (83.3%) caregivers reported being married, five (8.3%) reported being single or never married, three (5.0%) reported being separated or divorced, and two (3.3%) as partnered. The education level of these participants included 25 (41.7%) caregivers with graduate or professional degrees, 14 (23.3%) who completed some college, 13 (21.7%) with bachelor’s degrees, five (8.3%) with associate’s degrees, and 3 (5.0%) who completed high school.
Results regarding the family and child system were also obtained. The average number of children in the home was 1.83 (SD=.867), ranging from one to five children. 32 (53.3%) of the participants were females and 28 (46.7%) were males. 58 (96.7%) caregivers endorsed themselves as birth parents, one (1.7%) identified themselves as an adoptive parent, and one (1.7%) identified themselves as a foster parent. Results regarding household income were also ascertained. 17 (29.3%) participants endorsed an annual income within $50-74,999, 17 (29.3%) with an income of $100,000 or more, 11 (19.0%) with an income within $75,000-99,999, eight (13.8%) with an income within $25-49,999, and five (8.6%) with an income of $25,000 or less. Two participants (3.3%) did not indicate their estimated household income.

The average age of the target (or neuro-typically developed) child was 4.5592 (SD= 2.98021) and ranging from 15 months to 12 years. 55 (100%) caregivers rated their child (target child) as having no formal diagnosis of a mental health condition and five of the participants did not indicate if their child had received a formal diagnosis. Additionally, data pertaining to the types of individual or family healthcare or services utilized by caregivers at the time of their participation were obtained. 51 (85%) of caregivers reported receiving no sources of formal support, four (6.7%) indicated receiving multiple services, and with regard to parent support, parent-child therapy, family or child counseling, early
intervention services, and “Other” services, one (1.7%) caregiver indicated such services, respectfully, see, Table 1.

**Main Analysis**

To test hypotheses I through III, independent t-tests were conducted to compare the perceptions of parenting stress, parental competence, and relationship satisfaction in caregivers with a child with ASD and caregivers with a neuro-typically developed child. A significant difference was found in parenting stress in caregivers with a child with ASD ($M= 91.19, SD= 19.095$) and caregivers with a neuro-typically developed child ($M= 77.92, SD= 19.334; t (120) = 3.816, p=.000$). The magnitude of the differences in the means (mean difference= 13.227, 95% CI: 6.388-20.166) was large effect (eta squared = 0.108). However, it should be noted that while the two groups displayed a difference in mean total PSI-4-SF raw score, both ASD caregivers and Control caregivers indicated experiencing an average of normal parenting stress (Mean percentile score= 72% and 56%, respectively). With regard to caregiver relationship satisfaction, there was no significant difference found ($t (111) = .522, p = ns$) related to the average Relationship Assessment Scale scores; ASD caregivers ($M= 4.0104, SD= .81223$) and Control caregivers ($M=3.9381, SD= .65344$) both showed little relationship distress or dissatisfaction in their relationships. The magnitude of the differences in the means (mean difference= .07226, 95% CI: -.20185-.34657) was very small (eta squared = 0.002).
Comparison of each groups’ total scores revealed no significant difference in ASD caregivers ($M=68.18$, $SD=10.285$) and Control caregivers ($M=67.73$, $SD=10.528$; $t(124) = .242, p=ns$) regarding parental competence, or self-esteem, as both groups demonstrated an average of high perceived parental competence. The magnitude of the differences in the means (mean difference=.448, 95% CI:-3.224-4.121) was very small (eta squared = 0.004), see Table 2.

To investigate the predictability of perceptions of parental competence and relationship satisfaction (independent variables) and parenting stress (dependent variable) among caregivers with a child with ASD, a hierarchical multiple regression was employed for Hypothesis IV. Perceived parent sense of competence was entered at Step 1, explaining 40.2% (adjusted R Square=.390) of the variance in parenting stress. Entering relationship satisfaction into Step 2, created the combined model (parenting sense of competence and relationship satisfaction), which accounted for 44.6% (adjusted R Square=.423) of the variability in parenting stress. However, the addition of relationship satisfaction as a variable only accounted for an additional 4.4% of the variance in stress, when controlling for parent sense of competence. The results of the overall regression model were significant, as the variables together predicted parenting stress. (Model 1: $F(1, 49) = 32.906, p. <.000$; Model 2: $F(2, 48) = 19.298, p<.000$). Multicollinearity was not detected ($parenting competence$- tolerance = .924, VIF = 1.082; $relationship satisfaction$-tolerance= .924, VIF= 1.082). The parenting sense of competence
variable was a significant predictor of parenting stress ($\beta = -.574$, $p < .001$).

However, when controlling for parenting sense of competence, relationship satisfaction alone was not a significant predictor of parenting stress ($\beta = -.218$, $ns$), see Table 3.

Hypotheses V, VI and VII were analyzed with independent t-tests. With regard to hypothesis V, a significant difference was found between ASD Caregivers with a child age 7 and younger ($M= 87.90$, $SD= 16.531$) and ASD Caregivers with a child age 8 to 12 ($M= 98.10$, $SD= 22.513$) in that caregivers with an older child experienced more parenting stress ($t (60) = -2.014$, $p < .05$). The magnitude of the differences in the means (mean difference= -10.195, 95% CI: -20.322- -.069) was moderate (eta squared =.063). The current study did not find that caregivers with an older child demonstrate a higher parenting sense of competence than caregivers with a younger child (Hypothesis VI), ASD Caregivers with a child age 19 months to 7 years ($M= 69.73$, $SD= 9.437$) and ASD Caregivers with a child age 8 to 12 years ($M= 64.86$, $SD= 11.438$) did not significantly differ with regard to their ratings of parenting sense of competence [$t (64) = 1.826$, $p=.073ns$]. The magnitude of the differences in the means (mean difference= 4.876, 95% CI: -.459-10.211) was small (eta squared =.049). Finally, with regard to hypothesis VII, the age of the target child did not show a significant difference in relation to average relationship satisfaction scores of ASD Caregivers of a younger ($M= 4.1586$, $SD= .79088$) or older child ($M=3.7056$, $SD=.79044$, $t (53) =1.994$, $p =ns$). The
magnitude of the differences in the means (mean difference=.45309, 95% CI: -.00268-.90887) was moderate (eta squared =.069) see Table 4.

Hypotheses VIII through X were analyzed with the use of independent t-tests. With regard to the age of the caregiver and parent stress (Hypothesis VIII), the study did not reveal significant differences between younger (18 to 39 years old; $M=86.87$, $SD=17.381$) and older caregivers (40 years or older; $M=95.30$, $SD=21.253$; $t(56)=-1.660, p=ns$). The magnitude of the differences in the means (mean difference= -8.425, 95% CI: -18.590-1.739) was small (eta squared =.046).

Pertaining to hypothesis IX, that older caregivers are likely to have higher levels of perceived parent competence than younger caregivers, the current study revealed no significant difference [ $t(60)=.175, p=.862$] in parental competence in younger ($M=68.56$, $SD=9.866$) and older ($M=68.08$, $SD=11.665$) caregivers. The magnitude of the differences in the means (mean difference= .479, 95% CI: -.5.006-5.963) was small (eta squared =.049). The idea that relationship satisfaction relates to parent stress (Hypothesis X) was not supported in this study, as relationship satisfaction did not significantly differ between younger ASD caregivers ($M=4.1359$, $SD=.75121$) or older ASD caregivers ($M=3.7960$, $SD=.85194$, $t(50)=1.529, p=ns$). The magnitude of the differences in the means (mean difference= .33993, 95% CI: -.10670-.78655) was small (eta squared =.0446), see Table 5.

Hypotheses XI was also analyzed with an independent t-test. Consistent with previous findings (e.g., Bebko, Konstantareas, & Springer, 1987), there was no
significant difference in level of stress as indicated by PSI-4-SF Total Score in relation to whether the child was female ($M=90.20, SD=18.401$) or male ($M=91.51, SD=19.495, t(60) = -0.230, p=ns$). The magnitude of the differences in the means (mean difference= -1.311, 95% CI: -12.727-10.105) was small (eta squared =.028), see Table 6.
CHAPTER 6: DISCUSSION

There are several significant results arising from the study. A significant difference in parenting stress across both groups of participants was found to be robust, despite the small sample size of the groups. As such, the hypothesis regarding differences between caregivers with a child with ASD versus caregivers with a neuro-typically developed was supported. This shows that while both groups did not indicate clinically significant elevations of parenting stress, the average number of caregivers of a child with ASD endorsed experiencing significantly more parenting stress than the average number of caregivers with a child who is neuro-typically developed. This difference in parenting stress levels addresses the need for psychological variables in caregivers when assessing or treating a child. While a significant difference was found among the two groups, results should be interpreted with caution since the current group is not representative of a national sample.

With respect to higher levels of perceived parent competence and relationship satisfaction as predictors of lower levels of parenting stress, hypothesis IV was also supported. Perceived parental competence and relationship satisfaction together negatively predicted parenting stress scores in caregivers who have a child with ASD. It should be emphasized that relationship satisfaction, alone, did not significantly relate to parenting stress. While a significant relationship was found
between the three parenting variables, causation cannot be inferred and it remains unclear of the dynamic and transactional characteristics of these variables. Although a causal link between parenting stress, perception of parental competence, and relationship satisfaction cannot be made, the relationship found in the results of this study support the need to address these variables in addition to parenting stress when assessing and treating children. The relationship of such variables warrants further investigation into determining the generalizability of these results. It is important to note that a hierarchical multiple regression was selected in order to evaluate predictor variables separately. This analysis provides more information regarding the nature of the relationship. Research has demonstrated that parental competence has been consistently related to parenting stress, while relationship satisfaction has demonstrated mixed results (Rodrigue, Morgan, & Geffken, 1990; Kazak & Marvin, 1984; Bristol, Gallagher, & Schopler, 1988; Brobst, Clopton, & Hendrick, 2009).

The current study identified one significant result among hypotheses V through VII. Caregivers with an older age child (ages eight to twelve), demonstrated moderately more parenting stress compared to caregivers with a child with ASD seven years or younger. While the finding that having an older child with ASD related to higher parenting stress levels conflicts with previous findings,
the significance of this result yields helpful information when gathering information regarding the child receiving treatment.

Non-significant results were also revealed. First, with regard to perceptions of parenting competence and relationship satisfaction, no significant differences were found between the ASD Caregivers and the Control group. Second, the hypothesis that the gender of the child would not impact an ASD caregiver’s parenting stress level was confirmed (i.e., no significant difference in parenting stress levels with caregivers who had a female or male child with ASD).

In addition to child characteristics, psychosocial and demographic caregiver variables have been shown in some studies to impact parenting stress, competence and relationship satisfaction. With regard to the hypotheses VIII-X, results indicate that there was no significant relationship between the age of the caregiver with a child with ASD, parenting stress, parenting sense of competence, and relationship satisfaction. This finding is not surprising granted the mixed results of the literature.

Limitations

While results pertaining to hypotheses III, IV, and V were confirmed, discussion of several limitations is warranted. First, the participants obtained were selected from different methods of recruitment (i.e., internet, community family events, and an autism treatment center), which may have impacted demographic
variables such as race, age, education, and income level. For instance, many of the participants from the Control sample were affiliated with the researcher’s institution, and reported higher education and income levels such as such as graduate degrees and incomes above $75,000.

Additionally, the study utilized samples of convenience that were relatively small in size, such that caregivers with a child with ASD were mainly selected from a single autism treatment center and therefore, are not representative of the general population of caregivers of a child with ASD.

Caregivers who visit community health events or those who are seeking multiple medical evaluations for mood or behavioral disorders may demonstrate more awareness of their parental competence or satisfaction with their partner in addition to providing more time or other resources on their child. For these reasons, caution must be used when interpreting findings of from the groups in this study to the broader community. It would be interesting to examine time spent with a child or partner in relation to one’s parenting stress level.

While parenting stress was identified to be higher in the clinical group, additional psychosocial variables (i.e., relationship satisfaction, parental competence) were not significantly different from those of the Control group. This may indicate that while caregivers with a child with ASD experience more stress, they endorse similar ratings regarding parenting competence or relationship satisfaction as caregivers with a neuro-typically developed child. The question
remains as to whether these factors are critical in handling difficult situations related to raising a child with a disability.

Perhaps raising a child with ASD involves seeking/obtaining additional tools related to the role of caregiving. In the same respect, relationship satisfaction may maintain or contribute to normal stress levels in caregivers, but satisfaction may also be negatively affected by the stressors associated in raising a child with ASD. Therefore, programs may use this information by incorporating interventions for caregivers aimed at reducing stress, increasing sense of ability in handling parenting tasks, increasing parenting satisfaction, and increasing closeness with partners.

While the assessments utilized for this research have demonstrated strong psychometric properties, there may be more methodologically sound steps that can be taken to obtain reliable and valid participant responses. Most notably, participants commented about the ease in completing short assessments. However, longer assessment measures show greater reliability (Cureton, et al., 1973).

Additionally, the PSI-4-SF has been validated for children up to 12 years of age. Consequently, 9 participants from the ASD Caregiver group and two participants from the Control group were eliminated from data analyses. In addition, while the RAS is brief and convenient, it is possible participants may have responded in such a way as to present themselves or their relationship in a positive
light. This is a limitation associated with all measures used in the study, as many parents expressed discomfort in responding to items that were ‘personal.’ This feeling may have been increased in that many of the caregivers were seeking evaluations for their child and may have become offended when presented with measures assessing factors pertaining to the presence of distress or disturbance in themselves. Generally speaking, lengthier measures of functioning such as parenting self-esteem, mood or familial satisfaction may help to reduce social response bias or the way in which caregivers present themselves and also allow for stronger reliability and generalizability of results.

As research has shown a relationship between parenting stress and symptom or deficit severity level (Bebko, Konstantareas, & Springer, 1987; Konstantareas & Homatidis, 1989; Duarte, Bordin, Yazigi, & Mooney, 2005), the diagnosis and severity of child symptoms or problem behavior are important variables that warrant further research. The current study obtained information of these variables with the use of a 5-point Likert scale in which caregivers were instructed to subjectively rate their child’s symptom severity. As such, these variables were not incorporated into the statistical analyses. However, they are important in understanding caregiver experiences of parenting and their resulting effects on family functioning.
Currently, obtaining an objective understanding of a child’s diagnosis and symptom severity is a difficult task. Research has demonstrated that professionals may judge symptom severity differently than caregivers (Bebko, Konstantareas, & Springer, 1987). It would be important to determine a streamlined measure to use that captures the diagnosis and symptom severity of the child’s diagnosis, as recommended by other researchers, with the use of objective measurements, such as the Autism Spectrum Diagnostic Observation Schedule- Second Edition (ADOS-2; Lord, et al., 2012). Evidence-based observation tools, such as the ADOS-2, may be utilized to ascertain symptom severity and promote sound methodology in the examination of ASD and parenting variables.

Another potential limitation pertains to the collection of data for the Control group. Due to technical errors with the online survey, 26 participants did not provide their age and 21 participants did not indicate their gender. Therefore, caregiver age and gender differences between the two groups were not be obtained. It has been shown that caregiver age may be a significant factor in parenting variables such as parental stress (Delambo, Chung, & Huang, 2011; Konstantareas & Homatidis, 1989) and strain (Nolen-Hoeksema & Ahrens, 2002). It is worthwhile to investigate caregiver age in understanding caregiver variables associated with a child with ASD. Caregiver age may also involve a host of other variables such as cultural identity (Delambo, Chung, & Huang, 2011).
Finally, there are several possible variables outside the scope of this study that may impact parenting stress, perceived parental competence, and relationship satisfaction, or a combination of these variables. These include, but are not limited to, familial psychiatric history, additional life stressors (e.g., financial strain or loss of a family member), occupational stress, and relationships outside of the home. More research is needed in the area of parent and familial stressors that are associated with raising a child affected by ASD.

**Implications**

The implications of these findings are especially helpful in understanding that treatment must be viewed not only in terms of the individual affected, but also the individual’s family. There has been increasing research in the area of caregiver participation in a child’s treatment. It is important to understand the experience of a caregiver for full participation in treatment and to obtain meaningful outcomes (Kundert & Trimarchi, 2006). This study is important as it builds on research investigating child treatment outcomes in relation to parenting stress, relationship satisfaction, and parenting competence. Parenting stress level, though not clinically significant, was higher in caregivers with a child with ASD versus caregivers with a neuro-typically developed child. Clinicians and other medical care providers must be cognizant of parenting stress and accompanying difficulties in the family system and treatment caregiver involvement in intervention. Care should not only be given
to treatment of the child, but of the individuals providing care. Programs that include parent training may help to boost perceived competence and positively impact the stress a caregiver experiences.

With less parenting stress, parents’ motivation and participation in treatment are likely to increase. For example, Feinberg, et al. (2013) found that mothers obtaining treatment services that addressed parental distress and depressive symptoms were significantly less likely than those caregivers serving as controls to experience clinically significant parental stress. A significant reduction in mean depressive symptoms was found.

Since self-esteem related variables such as perceptions of parenting competence in addition to interpersonal relationships have been shown to impact caregiver’s mood and stress level (Karst and Vaughan Van Hecke, 2012), clinical activities, such as initial evaluations or behavioral treatment sessions, should incorporate parent support/training programs in order to maintain or boost caregiver well-being. These findings also push for further investigation into programs in which parent-child interaction is emphasized. In general, treatment outcomes not only pertain to the child, but also of the caregiver and/or couple, thus impacting familial areas of the child’s life and increasing positive feelings, interactions, and relationships within and across all family members.
**Future Directions**

There are many paths that can be taken with regard to parenting stress in caregivers who have a child with ASD. Acknowledging the benefits and limitations of the study allows us to understand that parental variables are an important area of investigation, even when the primary client receiving treatment is the child. Parenting stress is heightened in caregivers with a child with ASD and factors such as parental competence and relationship satisfaction are at play. Understanding why is another continued path that research in this area should follow. A start may lie in extending the current study in an effort to determine interactions between parenting stress, relationship satisfaction, perceived parental competence, or other variables related to the mental status of the caregiver.

More research is needed to determine objective methods to obtain information related to the experiences of caregivers. While self-report measures have been used extensively in the area of family research, these measures often fail to capture the entire parameter of a caregiver’s life and experiences. Also, it is likely that caregivers often respond in a positive light regarding personal matters such as relationship satisfaction or parental competence, especially when the focus is on the child. Additional naturalistic observations or extended interviews with caregivers and other family members may be useful when gathering information via
interview or self-report. This may also increase the validity of measuring personal parenting variables. Though the process may require more time and effort, and consequently resources, evidence may be obtained that reveals accurate and clear indications of caregivers’ experiences in raising a child with ASD.

ASD affects over 2 million people in the U.S. (Autism Speaks, 2013). It is not surprising that the disorder is often conceptualized as a ‘puzzle’ (Autism Speaks, 2013), comprised of several interacting environmental and biological variables. While the current study acknowledged psychosocial variables in caregivers, further investigation using additional methods of analyses might be warranted to capture the multidirectional relationship of the aforementioned variables. Karst and Vaughan Van Hecke (2012) suggest, “…intricate modeling techniques [such as multilevel modeling, structural equation modeling, and path analysis]…help capture the complex and dynamic factors within families that impact the development of children with ASD” (p. 257). Although these procedures are outside the scope of the current study, a relationship between parenting stress, perceived competence, and relationship satisfaction have been tentatively identified. The current study has contributed to the literature available in understanding caregivers’ lives in relation to raising a child with ASD. We hope these findings will positively impact the manner in which recommendations for treatment are prescribed.
References


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APPENDIX A: TABLES 1-6

Table 1: Descriptive Analyses

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<thead>
<tr>
<th></th>
<th>ASD Caregivers (N= 68)</th>
<th>Control (N=60)</th>
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</thead>
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<tr>
<td></td>
<td>N</td>
<td>%</td>
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<tr>
<td>Caregiver Gender</td>
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<tr>
<td>Female</td>
<td>49</td>
<td>73.1</td>
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<tr>
<td>Male</td>
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<td>26.9</td>
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<td>Caregiver Ethnicity</td>
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<td>Black/African American</td>
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<td>Partnered</td>
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<tr>
<td>Completion of High School</td>
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<td>Some College Completion</td>
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<td>Unknown</td>
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| Caregiver Type |  |
|----------------|--|--|--|--|
| Birth parents  | 60 | 89.6 | 58 | 96.7 |
| Grandparent    | 3  | 4.5  | 0  | 0.00 |
| Adoptive parent| 2  | 3.0  | 1  | 1.7  |
| Foster parent  | 0  | 0.00 | 1  | 1.7  |
| Siblings       | 2  | 3.0  | 0  | 0.00 |

| Target Child Gender |  |
|---------------------|--|--|--|--|
| Female              | 18 | 26.5 | 32 | 53.3 |
| Male                | 50 | 73.5 | 28 | 46.7 |

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<th>Child’s Diagnosis</th>
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<td>Seeking Evaluation</td>
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<td>12.3</td>
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<td>ASD</td>
<td>53</td>
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<td>Secondary ADHD</td>
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<td>Very Mild</td>
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63
Mild 19 41.3
Moderate 18 39.1
Severe 1 2.2
Very Severe 2 4.3
None 1 2.2

Services
Multiple sources 36 63.2 4 6.7
Early intervention 5 8.8 1 1.7
Family/child counseling 2 3.5 1 1.7
Other 2 3.5 1 1.7
Self/Community 1 1.8 0 0.00
Parent-Child 1 1.8 1 1.7
Parent Education 1 1.8 0 0.00
Parent Support 0 0.00 1 1.7
None 9 15.8 51 85.0

Table 2. Independent T-Tests for Hypotheses I-III

<table>
<thead>
<tr>
<th>Variable</th>
<th>Group</th>
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<th>Std. Dev.</th>
<th>t</th>
<th>Sig. (2-tailed)</th>
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<td>Parenting Stress</td>
<td>ASD</td>
<td>91.19</td>
<td>19.095</td>
<td>3.816</td>
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<td></td>
<td>Control</td>
<td>77.92</td>
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<td>ASD</td>
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<tr>
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<td>4.0104</td>
<td>.81223</td>
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<td>3.9381</td>
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Note: *p < .05, **p < .01

Table 3. Summary of Hierarchical Regression Analysis for Variables predicting Parenting Stress

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<thead>
<tr>
<th>Variable</th>
<th>β</th>
<th>R2</th>
<th>Adj. R2</th>
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<tr>
<td>Step 1 Competence</td>
<td>-.574***</td>
<td>.402</td>
<td>.390</td>
<td>32.906</td>
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<td>Step 2 Competence</td>
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<tr>
<td>Variable</td>
<td>Group</td>
<td>Mean</td>
<td>Std. Dev.</td>
<td>t</td>
<td>Sig. (2-tailed)</td>
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<tr>
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<td>--------</td>
<td>------</td>
<td>-----------</td>
<td>-------</td>
<td>----------------</td>
</tr>
<tr>
<td>Parenting Stress</td>
<td>Younger</td>
<td>87.90</td>
<td>16.531</td>
<td>-2.014</td>
<td>*</td>
</tr>
<tr>
<td></td>
<td>Older</td>
<td>98.10</td>
<td>22.513</td>
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<tr>
<td>Sense of Competence</td>
<td>Younger</td>
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<td></td>
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<td>64.86</td>
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<td>3.7056</td>
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Note: *p < .05, **p < .01

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<th>Mean</th>
<th>Std. Dev.</th>
<th>t</th>
<th>Sig. (2-tailed)</th>
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<td>Parenting Stress</td>
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<td>86.87</td>
<td>17.381</td>
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<td>Older</td>
<td>95.30</td>
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<td>Older</td>
<td>68.08</td>
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<tr>
<td>Relationship Sat.</td>
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<td>4.1359</td>
<td>.75121</td>
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<td>Older</td>
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Note: *p < .05, **p < .01

<table>
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<tr>
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<th>Group</th>
<th>Mean</th>
<th>Std. Dev.</th>
<th>t</th>
<th>Sig. (2-tailed)</th>
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<tbody>
<tr>
<td>Parenting Stress</td>
<td>Female</td>
<td>90.20</td>
<td>18.401</td>
<td>-.230</td>
<td></td>
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<tr>
<td></td>
<td>Male</td>
<td>91.51</td>
<td>19.459</td>
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</table>

Note: *p < .05, **p < .01
APPENDIX B: INSTITUTIONAL REVIEW BOARD

Notice of Exempt Review Status

From: Florida Tech Institutional Review Board
FWA00014339, Exp. 4/11/2017, H000001690

To: Nicole Kline

Date: January 29, 2013

IRB Number: 13-004

Study Title: Assessing caregiver competence, stress, and relationships for children on the autism spectrum

Dear Researcher:

Your research protocol was reviewed and approved by the IRB Chairperson. Per federal regulations, 45 CFR 46.101, your study has been determined to be minimal risk for human subjects and exempt from 45 CFR46 federal regulations and further IRB review or renewal unless you change the protocol or add the use of participant identifiers. This study is approved for one year from the above date. If data collection continues past this date, a Continuing Review Form must be submitted.

All data, which may include signed consent form documents, must be retained in a locked file cabinet for a minimum of three years (six if HIPAA applies) past the completion of this research. Any links to the identification of participants should be maintained on a password-protected computer if electronic information is used. Access to data is limited to authorized individuals listed as key study personnel.

The category for which exempt status has been determined for this protocol is as follows:

2. Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior so long as confidentiality is maintained.
   a. Information is recorded in such a manner that the subject cannot be identified, directly or through identifiers linked to the participant and/or
   b. Subject’s responses, if known outside the research would not reasonably place the subject at risk of criminal or civil liability or be damaging to the subject’s financial standing, employability, or reputation.
### RESEARCH INVOLVING HUMAN SUBJECTS

**Expedited/Full Application**

This information listed below should be submitted to Florida Tech's IRB if the proposed research has more than minimal risk (none of the Exempt conditions apply) or if the research utilizes a special population (children, prisoners, institutionalized individuals, etc.).

#### Part 1 – General Information

<table>
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<th>Assessing Caregiver Competence, Stress, and Relationships for Children on the Autism Spectrum</th>
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<td>Expected Project Start Date:</td>
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<tr>
<td>Expected Project Duration:</td>
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<table>
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<tr>
<th>Principal Investigator:</th>
<th>Nicole Kline</th>
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<tbody>
<tr>
<td>Title:</td>
<td>Clinical Psychology Graduate Student</td>
</tr>
<tr>
<td>Academic Unit:</td>
<td>School of Psychology</td>
</tr>
<tr>
<td>Phone:</td>
<td>(440)382-7349</td>
</tr>
<tr>
<td>Email:</td>
<td><a href="mailto:nkline2010@mv.fit.edu">nkline2010@mv.fit.edu</a></td>
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<table>
<thead>
<tr>
<th>Co Investigator:</th>
<th>Ivy Chong, Ph.D., BCBA-D</th>
</tr>
</thead>
<tbody>
<tr>
<td>Title:</td>
<td>Director of Autism Services and Training</td>
</tr>
<tr>
<td>Academic Unit:</td>
<td>Assistant Professor, ABA Program</td>
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<td>Phone:</td>
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<td>Email:</td>
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<td>Email:</td>
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</table>
### Part 2 - Project Sponsorship Information (current or planned)

1. Is the research to be funded with federal funds, or are federal funds being applied for?  
   - Yes  
   - No  
   - Name of Funding Source  
   - X  

   If yes, please provide one copy of the grant proposal.

2. Is the research to be funded by a private sponsor?  
   - Yes  
   - No  
   - Name of Funding Source  
   - X

### Part 3 - Other Study Information

1. Is this a clinical research project? (Definition: Clinical Research Involving Human Subjects means any research or medical procedure involving human subjects or the use of human samples for the development and evaluation of patient therapies, such as diagnostic tests, drug therapies, or medical devices. It includes clinical trials.)  
   - Yes  
   - No  
   - X

2. Do any project personnel receive incentives for recruiting human subjects or for any other purpose directly related to the study?  
   - Yes  
   - No  
   - X

3. Does the research involve the collection of data concerning:  
   - Minors (18 years or under)?  
   - Yes  
   - No  
   - X
   - Prisoners?  
   - Yes  
   - No  
   - X
   - Fetuses, pregnant women, or information about human in vitro fertilization?  
   - Yes  
   - No  
   - X
   - The cognitively impaired?  
   - Yes  
   - No  
   - X
   - Subjects who are institutionalized (e.g., in a mental health facility, nursing home, or halfway house)?  
   - Yes  
   - No  
   - X

4. Will the study elicit data about subjects engaged in illegal or stigmatizing behaviors (e.g., illicit drug use, child abuse, alcoholism, or gambling)? If so, provide an explanation in the study description.  
   - Yes  
   - No  
   - X

5. Does the research involve deception of the subjects by the researcher? If so, discuss why deception is necessary in the study description.  
   - Yes  
   - No  
   - X

6. Does the research involve:  
   - Non Florida Tech researchers?  
   - Yes  
   - No  
   - X
   - Collection of images or audio recordings of the subjects?  
   - Yes  
   - No  
   - X
   - Will the study target or exclude a particular gender or ethnic or racial group?  
   - Yes  
   - No  
   - X

7. Will the research be conducted outside of the United States?  
   - Yes  
   - No  
   - X

### Part 4 - Research Description

1. In lay terms, please describe the GENERAL PURPOSE of the study and how human subjects will be involved. List the SPECIFIC AIMs and RESEARCH QUESTIONS or HYPOTHESES.

   The general purpose of the study is to assess how parents with children with autism view themselves in regards to parental competency, their stress level in raising a child with an autism spectrum disorder, and their relationship satisfaction. Because literature has presented
mixed findings pertaining to these factors in families of children with autism, further research is warranted. The following hypotheses have been developed: a) parents with a child (ren) on the autism spectrum will view themselves as less competent than those parents with typically developed children, b) parents with children with an autism spectrum disorder will report higher parenting stress than those of typically developed children, c) Couples of children with an autism spectrum disorder will report less marital or relationship satisfaction than the control population. It is also hypothesized that older parents of children with autism will report less difficulties in the competency and marital realms as well as report less stress than those younger parents.

2. Outline the INCLUSION CRITERIA for subjects, explaining the rationale for the involvement of any special groups including children, prisoners, pregnant women, or subjects with cognitive impairments. Describe the characteristics of the targeted subjects, including gender, age ranges, ethnic background, and health/treatment status. If women or minorities are excluded, provide written justification. Give the number of subjects you anticipate including from each targeted group listed above.

For the ASD parent population: There are no special inclusion criteria. Participants may be male or female, ages 18 to 60 years-old. Parents must have at least one child affected by an autism spectrum disorder. The sample size needed is minimally 70 participants.

For the control group: parents with a typically developed child or children will serve as a control. There are no special inclusion criteria for the study. Participants in this group must be between the ages of 18 and 60 and can be male or female. The sample size needed is minimally 70 participants.

3. Describe sources for potential participants, how subjects will be RECRUITED or the sampling procedures. Attach recruitment advertisement(s) if applicable.

Control group participants will be recruited through health fair events or other places of public domain (e.g., Brevard County Tax Collector’s Office, public libraries). The Florida Institute of Technology’s Fit Forum may also be a source of recruitment for participants in the comparative sample. Participants who have a child or children with an ASD will be recruited through services provided by Florida Institute of Technology’s Scott Center for Autism and the Scott Center for Autism’s ASD Practicum. Organizations such as the Center for Autism Related Disabilities (CARD) organization and other organizations that advocate for parents and children with developmental disabilities may also be contacted to help recruit participants through advertisement of research at autism-related events. Additional sources of sampling will include caregiver access to the study by the use of Internet and in-home visits to accommodate caregivers who may find it more feasible to complete the study in their own home. The services families receive will not be contingent upon their willingness to participate in the study.

4. Describe any COMPENSATION the subjects will receive, including course credit. If monetary compensation is offered, indicate how much the subjects will be paid and describe the terms of payment.
7. Describe all SITES where this research will take place and attach documentation of permission from the appropriate source if the study involves subjects from places other than common public spaces.

Agreement from the Florida Institute of Technology’s Scott Center for Autism if IRB approval is met. (See attached for documentation of conditional permission).

8. Describe any POTENTIAL RISKS (physical, psychological, social, legal or other) and the steps that will be taken to minimize risk. Where appropriate, discuss provisions for ensuring necessary medical or professional intervention in the event of adverse effects to the subjects. Also, where appropriate, describe the provisions for monitoring the data collected to ensure the safety of subjects. Research involving children must carefully assess risks and describe the safeguards in place to minimize these risks.

The risks that can arise from the study are potential negative emotions parents may experience while responding to questionnaire items related to the stress of caring for a child with autism. Contact information of the researcher will be provided to participants if they have questions or would like to know the results of the study. Furthermore, parents may inquire about their specific results of the questionnaires. If so, an overview of their results will be given. Participants will have the opportunity to discuss their feelings or attitudes about the study with the researcher and community support contact information will be offered.

9. Discuss the importance of the knowledge that will result from your study and what benefits will accrue to your subjects (if any). Discuss why the risks to subjects are reasonable in relation to the anticipated BENEFITS to subjects.

The knowledge that can be obtained from this study will contribute to the investigation of those affected by autism spectrum disorders, specifically parents and caregivers. The unique aspect of this study is that attention will be paid to possible family and environmental variables that greatly influence developmental outcomes for children on the autism spectrum. Determining factors that add to parental competency, stress and so forth are crucial to other areas related to the study of ASD, including early intervention programs/services. The benefits of this study far outweigh negative consequences involved in that the items of the questionnaires, while addressing personal matters, are thought to be things that parents already think much about (such as difficulties and/or stress surrounding caring for their children, finding time for relaxation, and interpersonal relationship qualities).

10. CONSENT. Informed consent can be in either written or oral format. If you request waiver of informed consent, documentation of informed consent, or of written informed consent, please state your justifications. Attach consent form if applicable. If an oral consent is planned, attach a copy of the text of the statement. (Consent form should contain all eight elements listed in Part 5).

Informed participant consent will be in written format. See attached.

Part 5 - INSTRUCTIONS FOR DOCUMENTATION OF INFORMED CONSENT
Participants of this study will not be compensated. However, once participating in the study, parents will be entered in a lottery for a chance to win a resource book about parent training: Clark, L. (2005). SOS Help for parents: A practical guide for handling common everyday behavior problems. (3rd edition). SOS Programs & Parents Press.

5. Explain how CONFIDENTIALITY and privacy of participant data (and anonymity if appropriate) will be maintained. If the research study involves collection of images or audio recordings of subjects, explain how the material will be used, who will see the images or hear the recordings, and in what setting.

Confidentiality of parents will be explained to parents in the informed consent (identifiable information will not be used as data). Means of protecting participants' confidentiality also involves coding of the questionnaires by numbers and secure storage of data. Any limits to confidentiality will also be discussed. The informed consent will include the purpose, procedure, duration of experiment, potential risks (minimal to none), and a statement that the experiment is voluntary and the participant may withdraw themselves from the study at any time.

6. Describe the study design/research/measurement PROCEDURE (e.g., control and experimental groups, etc.). Indicate whether or not the subjects will be randomized for this study. Discuss how you will conduct your study, and what measurement instruments you are using. Attach a copy of any questionnaires, measurement instruments, interview protocols, or a description of topics or an approximate script that will be used. If not available at this time, explain. Deceptive techniques must be justified by the study’s prospective scientific, educational, or applied value, and the investigator should explore equally effective alternative procedures that do not use deception and a debriefing process must be discussed here.

Please describe your study in enough detail so the IRB can identify what you are doing and why.

There will be two groups in which data will be collected: a group of participants that have a child or children with an autism spectrum disorder as well as a control group consisting of parents with a typically developed child or children. Data pertaining to parental stress, competency, and relationship satisfaction will be acquired via the use of three questionnaires and a demographic survey:

1) Demographic Survey
2) Parental Stress Index/Short-Form (PSI-SF) (Abidin, 1995)
3) Parenting Sense of Competence Scale (PSOC) (Johnson & Mash, 1989)
4) Relationship Assessment Scale (RAS) (Hendrick, S, 1988)

Respondents will be given a written informed consent form prior to responding to the questionnaires. Upon completion of the questionnaires, respondents will be given a debriefing form to read which will review the purpose of the experiment and the predicted hypotheses. In addition, contacts for external support will be given as well as the permission to contact the researcher for information, questions or concerns.
Informed consent is one of the primary ethical requirements underlying human subjects' research, reflecting the principle of respect for potential subjects. Informed consent assures that prospective human subjects understand the nature of the research and can decide knowledgeably and voluntarily whether or not to participate.

Informed consent refers to the voluntary choice of an individual to participate in research based on an accurate and complete understanding of, among other things, its purposes, procedures, risks, benefits, alternatives, and any other factors that may affect a person's decision to participate.

The basic concepts of the consent process include:

- Full disclosure of the nature of the research and the subject's participation, adequate comprehension on the part of the potential subject
- Voluntary choice to participate
- Informed consent must be documented by use of a written consent form approved by the IRB and signed by the participant or the participant's legally authorized representative. A copy should be given to the person signing the form. Even though the IRB has approved a consent procedure, it is the investigator's responsibility to ensure that each potential subject understands the information and to take the appropriate steps necessary to gain that comprehension.

Individuals may not be involved as research participants unless a) they understand the information that has been provided and informed consent has been obtained, or b) the IRB has approved a waiver for informed consent.

REMEMBER: if the participant is under the age of 18, parental consent is required. This includes college students under the age of 18.

If the research involves the participation of minors (under 18 years of age), read the description of requirements for research involving children. Additional requirements concerning parental consent forms and child assent are discussed.

Please follow the instructions for documentation carefully.

1. The consent form should be written in language that the participants can understand. Whenever possible, simple declarative sentences should be used. Ordinary language should explain technical terms.
2. Avoid the use of exculpatory language through which the subject or the representative is made to waive or appear to waive any of his/her legal rights or release the investigator, sponsor or institution or its agents from liability for negligence.
3. Important information that must be included on the Consent Form:
   a) Purpose of the research
   b) Procedures to be followed (what will the participants be asked to do? Include physical requirements or experimental procedures if applicable.)
   c) Foreseeable risks or discomforts to the subjects. What are the risks associated with participating and what safeguards are in place? Include the following statements, where appropriate:
      "In the event of physical injury resulting from the research procedures, no form of compensation is available. Medical treatment may be provided at your expense or at the expense of your health care insurer (i.e., Medicare, Medicaid private payor) which may or may not provide coverage. If you have questions it is your responsibility to contact your
insurer.

d) Benefits to the subject or others which may reasonably be expected to result

e) Alternative procedures or alternatives to participation if any

f) Level of confidentiality of participant records. Is data anonymous? How will data be stored? If audio or visual records are obtained how will they be maintained? Who will have access to the data?

g) Primary investigator's contact information. Point of contact for questions or problems related to this study.

h) IRB contact. Also note the study was approved by Florida Institute of Technology's IRB and list the current IRB Chair and his/her contact information for questions about the rights of people who take part in research.

Voluntary participation, refusal, and withdrawal. Include the following statement:

"Participation is voluntary. Refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled. You may discontinue participation at any time without penalty or loss of benefits to which you are otherwise entitled."

i) Signatures, if appropriate. Provide a place for:

   a) Signature of the participant (or his/her legally authorized representative)

   b) Date of signature

Waiver of Informed Consent

The IRB may approve a consent procedure that does not include, or which alters, some or all of the elements of informed consent outlined above, or waive the requirements to obtain informed consent provided the IRB finds and documents that the following four conditions have been met:

• The research involves no more than minimal risk to the subjects;

• The waiver or alteration will not adversely affect the rights and welfare of subjects;

• The research could not practically be carried out without the waiver or alteration; and

• Whenever appropriate, the subjects will be debriefed — provided with additional pertinent information — after they have participated in the study.

Part 6: SIGNATURE ASSURANCE SHEET

Principal Investigator's Assurance Statement:

I understand Florida Institute of Technology's policy concerning research involving human subjects and I agree:

1. to accept responsibility for the scientific and ethical conduct of this research study.

2. to obtain prior approval from the Institutional Review Board before amending or altering the research protocol or implementing changes in the approved consent form.

3. to immediately report to the IRB any serious adverse reactions and/or unanticipated effects on subjects which may occur as a result of this study.

4. to complete, on request by the IRB, a Continuation Review Form if the study exceeds its estimated duration.

PI Signature ___________________________ Date 8/3/10
Advisor Assurance: If primary investigator is a student
This is to certify that I have reviewed this research protocol and that I attest to the scientific merit of the study, the necessity for the use of human subjects in the study to the student’s academic program, and the competency of the student to conduct the project.

Major Advisor: Ivy Chong

Date: 12/6/12

Academic Unit Head: It is the PI’s responsibility to obtain this signature.
This is to certify that I have reviewed this research protocol and that I attest to the scientific merit of this study and the competency of the investigator(s) to conduct the study.

Academic Unit Head: [Name]

Date: 1-10-13

FOR IRB USE ONLY

IRB Approval

Name: [Name]

Date: 1-29-13

IRB #

Florida Tech IRB: November 2005
APPENDIX C: INTRODUCTORY LETTER AND INFORMED CONSENTS

Dear Parents and Caregivers,

We are examining level of stress and available support for parents of children diagnosed with an autism spectrum disorder (ASD) and would like to invite you to participate. Participation in this study will require completion of surveys and questionnaires about your child’s development, parenting issues you have experienced, and any challenges associated with raising a child with ASD. To participate, you must be a parent or caregiver of a child (under age 18) who may be suspected of or diagnosed with an ASD (including: Autistic Disorder, Pervasive Developmental Disorder NOS, or Asperger’s Disorder). The diagnosis must have been previously identified by a pediatrician, psychologist or other licensed professional. Perceived stress levels will be compared with caregivers who do not have a child on the autism spectrum. Identifying information collected during the course of this study will be kept strictly confidential and data will be kept securely in a locked cabinet in a locked room, solely for the purpose of this study.

We believe this study will provide better understanding of the challenges that parents of children diagnosed with an ASD experience. A summary of the findings will be provided upon request at the conclusion of the study. If you have any questions or concerns, please contact Nicole Kline at: nkline2010@my.fit.edu.

Thank you for your time in advance.

Nicole Kline, M.S.
Doctoral Student
Florida Institute of Technology

Ivy Chong, Ph.D., BCBA-D
Licensed Psychologist #8214
Director of Autism Services & Training
The Scott Center for Autism Treatment
College of Psychology and Liberal Arts
Faculty Supervisor: ichong@fit.edu
Informed Consent

Procedure, Duration of Participation, & Approximate Number of Participants: You are invited to participate in a study examining parental stress, perceived competence, and relationship satisfaction. We are interested in examining these variables for parents with typically developing children or a child suspected of or diagnosed with an Autism Spectrum Disorder. We are asking for your participation because you are at least 18 years old and have served as the primary caregiver to one or more children. While there are no direct benefits for taking part in this study, the information collected will be used to help better understand how parents are affected in regards to the aforementioned variables. We are also interested in determining whether stress, perceived competence and relationship satisfaction differ for parents with a child on the autism spectrum. This will be especially helpful for health care professionals when making recommendations for treatment. The current study will include a demographic survey, a 36-item scale addressing parental stress (for caregivers with a child 12 years or younger), a 16-item scale addressing perceived parenting competence, and a 7-item scale addressing relationship satisfaction. These questionnaires can be completed in an estimated 45 minutes.

Risks and Discomfort: The risks that can arise from the study are potential negative feelings while completing the questionnaires as sensitive issues regarding parenting and interpersonal relationships are assessed.

Confidentiality: All information will be kept confidential and your name or other identifying information will not appear on any form. This signed consent will be kept separate from your responses to the questionnaires.

Should you have any questions/concerns about this research, please feel free to contact Nicole Kline at nkline2010@my.fit.edu or faculty supervisor, Dr. Ivy Chong at ichong@fit.edu.

I have read the above information and I understand it. I understand that it is possible that I may experience minor distress after participation. After reading the information, I agree to participate in the current study. I understand that participation is voluntary. Refusal to participate or discontinuation of participation is voluntary. Refusal to participate or discontinuation of
participation at any time will involve no penalty or loss of benefits to which I am otherwise entitled.

_____________________________  __________________________
Participant’s Signature         Date
Print name

_____________________________
Participant’s Email Address

I have explained and defined in detail the research procedures in which the subject has consented to participate.

_____________________________  __________________________
Witness Signature              Date
Dear Parents and Caregivers,

We are examining level of stress and available support for parents of children diagnosed with an autism spectrum disorder (ASD) and would like to invite you to participate. Participation in this study will require completion of surveys and questionnaires about your child’s development and parenting issues you have experienced. To participate, you must be a parent or caregiver of a child (under age 12) who is typically developed. Perceived stress levels will be compared with caregivers who have a child on the autism spectrum.

We believe this study will provide better understanding of the challenges that parents in general face, but also those that parents of children diagnosed with an ASD experience. A summary of the findings will be provided upon request at the conclusion of the study. If you have any questions or concerns, please contact Nicole Kline at: nkline2010@my.fit.edu.

Thank you for your time in advance.

Nicole Kline, M.S.
Doctoral Student
Florida Institute of Technology

Ivy Chong, Ph.D., BCBA-D
Licensed Psychologist #8214
Director of Autism Services & Training
The Scott Center for Autism Treatment
College of Psychology and Liberal Arts
Faculty Supervisor: ichong@fit.edu
**Informed Consent**

**Procedure, Duration of Participation, & Approximate Number of Participants:**
You are invited to participate in a study examining parental stress, perceived competence, and relationship satisfaction. We are interested in examining these variables for parents with typically developing children or a child suspected of or diagnosed with an Autism Spectrum Disorder who are under the age of 12 years. We are asking for your participation because you are at least 18 years old and have served as the primary caregiver to one or more children. While there are no direct benefits for taking part in this study, the information collected will be used to help better understand how parents are affected in regards to the aforementioned variables. We are also interested in determining whether stress, perceived competence and relationship satisfaction differ for parents with a child on the autism spectrum. This will be especially helpful for health care professionals when making recommendations for treatment. The current study will include a demographic survey, a 36-item scale addressing parental stress, a 16-item scale addressing perceived parenting competence, and a 7-item scale addressing relationship satisfaction. These questionnaires should take no more than 30 minutes to complete.

**Risks and Discomfort:**
The risks that can arise from the study are potential negative feelings while completing the questionnaires as sensitive issues regarding parenting and interpersonal relationships are assessed.

**Confidentiality:**
All information will be kept confidential as no identifying information will be included in the study. Should you have any questions/concerns about this research, please feel free to contact Nicole Kline at nkline2010@my.fit.edu or faculty supervisor, Dr. Ivy Chong at ichong@fit.edu.

I have read the above information and I understand it. I understand that it is possible that I may experience minor distress after participation. After reading the information, I agree to participate in the current study. I understand that participation is voluntary. Refusal to participate or discontinuation of participation at any time will involve no penalty or loss of benefits to which I am otherwise
entitled. I understand that individual results are available to me upon my request to the principal investigator, Nicole Kline, M.S.

Please check box below to indicate if you agree to the Informed Consent above.

_________ Yes, I understand the informed consent and I agree to participate in the study.

Should you wish to receive results from the assessment measures you take, please write your email address:

________________________________________
# APPENDIX D: DEMOGRAPHIC QUESTIONNAIRE

## CAREGIVER SURVEY

### Demographic Information
Please complete the following:

- **Your age:** __________
- **Your gender:** Q Male  Q Female
- **Ethnicity:**
  - Q American Indian and Alaska Native
  - Q Asian
  - Q Black or African American
  - Q White
  - Q Native Hawaiian/Pacific Islander
  - Q Other
- **Highest degree of education:**
  - Q Less than 9th grade
  - Q Some high school (no diploma)
  - Q Associate degree
  - Q Bachelor's degree
  - Q Some college (no degree)
  - Q Graduate or professional degree
  - Q Other
- **Estimated household income:**
  - Q $21,000 to $40,999
  - Q $50,000 to $74,999
  - Q $75,000 or more
- **Marital status:**
  - Q Single/Never married
  - Q Divorced/Separated
  - Q Married
  - Q Partnered

Please tell us about the children living in your household.

**Child 1:**
- **Gender:** Q Male  Q Female
- **Age:** __________
- **Relationship to child:**
  - Q A Birth parent
  - Q Adoptive parent
  - Q Foster-parent
  - Q Grand/Great Grandparent
  - Q Other relative
  - Q Other

**Child 2:**
- **Gender:** Q Male  Q Female
- **Age:** __________
- **Relationship to child:**
  - Q A Birth parent
  - Q Adoptive parent
  - Q Foster-parent
  - Q Grand/Great Grandparent
  - Q Other relative
  - Q Other

**Child 3:**
- **Gender:** Q Male  Q Female
- **Age:** __________
- **Relationship to child:**
  - Q A Birth parent
  - Q Adoptive parent
  - Q Foster-parent
  - Q Grand/Great Grandparent
  - Q Other relative
  - Q Other

**Child 4:**
- **Gender:** Q Male  Q Female
- **Age:** __________
- **Relationship to child:**
  - Q A Birth parent
  - Q Adoptive parent
  - Q Foster-parent
  - Q Grand/Great Grandparent
  - Q Other relative
  - Q Other

**Child 5:**
- **Gender:** Q Male  Q Female
- **Age:** __________
- **Relationship to child:**
  - Q A Birth parent
  - Q Adoptive parent
  - Q Foster-parent
  - Q Grand/Great Grandparent
  - Q Other relative
  - Q Other

*If more than 5 children, please use space provided on the back of this sheet.*

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**Questionnaire Note:** If you have more than one child with a diagnosis (i.e., multiple children receiving services or support), rate the below listed items on the remainder of the questionnaire to the child with the **most severe diagnosis** or the child who requires the most **services or support** if you do not have a child with a formal diagnosis, please write "none" in the line below labeled "Other" and skip to the bold-headed line. "Identify the type of program."  

**Child's diagnosis:** (Check the primary diagnosis; if more than one, indicate which diagnosis is primary):  
- No Diagnosis  
- Autism Spectrum Disorder  
- ADHD  
- Anxiety  
- Mood Disorder  
- Cognitive Impairment (MR)  
- Other:  

Child's age when primary diagnosis was given:  

If your child has been diagnosed, please rate the severity of your child's symptoms (check one):  
- Very Mild  
- Mild  
- Moderate  
- Severe  
- Very Severe  

**Identify the type of program** that most accurately describes the services your child or your family is receiving. Check all that apply.  
- Parent Education  
- Parent Support Group  
- Parent/Child Interaction  
- Advocacy (self/community)  
- Fatherhood Program  
- Planned and/or Crisis Respite  
- Homeless/Transitional Housing  
- Resource and Referral  
- Family Resource Center  
- Social Skill Building/Ed for Children  
- Adult Education (i.e., GED/Ed)  
- Job Skills/Employment Prep  
- Pre-Natal Class  
- Family Literacy  
- Marriage Strengthening/Prep  
- Home Visiting  
- Behavioral Intervention Services  
- Family or Child Counseling  
- Academic Tutoring  
- Early Intervention Services  
- Other (If you are using a specific curriculum, please name it here):  
- None  

If you are currently receiving any of the services listed above, please indicate length of treatment (i.e., when it began),  

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APPENDIX E: PARENTING SENSE OF COMPETENCE SCALE

CAREGIVER SURVEY

Part 1. Listed below are a number of statements. Please respond to each item, indicating your agreement or disagreement with each statement in the following manner.

Parenting Sense of Competence Scale
If you strongly agree, check the letter SA
If you agree, check the letter A
If you mildly agree, check the letter MA
If you mildly disagree, check the letter MD
If you disagree, check the letter D
If you strongly disagree, check the letter SD

1. The problems of raising a child are easy to solve once you know how your actions affect your child, an understanding I have acquired.
   • SA  • A  • MA  • MD  • D  • SD

2. Even though being a parent could be rewarding, I am frustrated now.
   • SA  • A  • MA  • MD  • D  • SD

3. I go to bed the same way I woke up in the morning feeling I have not accomplished a whole lot.
   • SA  • A  • MA  • MD  • D  • SD

4. I do not know what it is, but sometimes I’m supposed to be in control, I feel more like the one being manipulated.
   • SA  • A  • MA  • MD  • D  • SD

5. My mother/father was better prepared to be a good mother/father than I am.
   • SA  • A  • MA  • MD  • D  • SD

6. I would make a fine model for a new mother/father to follow in order to learn what she/he would need to know in order to be a good parent.
   • SA  • A  • MA  • MD  • D  • SD

7. Being a parent is manageable, and any problems are easily solved.
   • SA  • A  • MA  • MD  • D  • SD

8. A difficult problem in being a parent is not knowing whether you’re doing a good job or a bad one.
   • SA  • A  • MA  • MD  • D  • SD

9. Sometimes I feel like I’m not getting anything done.
   • SA  • A  • MA  • MD  • D  • SD

10. I meet my own personal expectations for expertise in caring for my child.
    • SA  • A  • MA  • MD  • D  • SD

11. If anyone can find the answer to what is troubling my child, I am the one.
    • SA  • A  • MA  • MD  • D  • SD

12. My talents and interests are in other areas, not in being a parent.
    • SA  • A  • MA  • MD  • D  • SD

13. Considering how long I’ve been a mother/father I feel thoroughly familiar with this role.
    • SA  • A  • MA  • MD  • D  • SD

14. If being a mother/father of a child were only more interesting, I would be motivated to do a better job as a parent.
    • SA  • A  • MA  • MD  • D  • SD

15. I honestly believe I have all the skills necessary to be a good mother/father to my child.
    • SA  • A  • MA  • MD  • D  • SD

16. Being a parent makes me tense and anxious.
    • SA  • A  • MA  • MD  • D  • SD

APPENDIX F: RELATIONSHIP ASSESSMENT SCALE

CAREGIVER SURVEY

Relationship Assessment Scale

Part II. Please respond to each item, indicating your level of satisfaction with each statement in the following manner. Please mark the number for each item which best answers that item for you.

1. How well does your partner meet your needs?  
   - 1 Poorly  
   - 2 Average  
   - 3 Satisfied  
   - 4 Very Satisfied

2. In general, how satisfied are you with your relationship?  
   - 1 Poor  
   - 2 Average  
   - 3 Satisfied  
   - 4 Excellent

3. How good is your relationship compared to most?  
   - 1 Never  
   - 2 Average  
   - 3 Satisfied  
   - 4 Excellent

4. How often do you wish you hadn’t gotten into this relationship?  
   - 1 Only  
   - 2 Average  
   - 3 Completely  
   - 4 Often

5. To what extent has your relationship met your original expectations?  
   - 1 Not at all  
   - 2 Average  
   - 3 Completely  
   - 4 Satisfied

6. How much do you love your partner?  
   - 1 Not much  
   - 2 Average  
   - 3 Completely  
   - 4 Extremely

7. How many problems are there in your relationship?  
   - 1 Very few  
   - 2 Average  
   - 3 Many  
   - 4 Extremely

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Resources for Counseling/Crisis Intervention:

Community Psychological Services  
The Scott Center for Autism Treatment  
150 W. University Blvd.  
Melbourne, FL 32901  
(321) 647-8106 Ext. 2

Family Counseling Center of Brevard, Inc.  
840 Reed AVE.  
Rockledge, FL 32955  
(321) 632-5792  
www.fccbrevard.com

Women’s Center  
4231 Aurora Rd.  
Melbourne, FL 32935  
Phone: (321) 242-3110

Circles of Care—Psychiatric Services, Melbourne  
2020 Commerce Dr.  
Melbourne, FL 32901  
(321) 952-6000  
www.circlesofcare.org

Crisis Hotline of Central Florida  
(407) 425-2624

Autism and Parenting Sources:

The Family Source of Florida—24-Hour Parent Helpline  
423 N. Magnolia Dr.  
Tallahassee, FL 32308  
(800) 352-5683  
www.familysource.org

Center for Autism and Related Disabilities (CARD)  
University of Central Florida  
Orlando, FL 32816  
www.ucf-card.org

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